Appendix 1: SNOMED-CT and the ICF

SNOMED-CT

SNOMED-CT is regarded as the largest and most leading clinical terminology with more than 352,000 concepts, 939,000 synonyms, and 1,360,000 relationships. The College of American Pathologists (CAP) is holder of the copyright, trademark and patent rights in SNOMED-CT. The CAP owns the copyright in all editions of SNOMED, including the copyright in any allowable adaptations, the trademarks SNOMED and SNOMED CT, and any and all patent rights in SNOMED. However, a key element of the licensing agreement between the National Library of Medicine (NLM) and CAP was the continuing availability through the UMLS of the most recent version of SNOMED-CT should the NLM/CAP agreement not be renewed in the future.

Within the governance structure of the CAP, the SNOMED International Authority has the direct responsibility for terminology-related activities. It establishes strategic direction for the CAP's clinical terminology activities, advises management, monitors division performance, and provides connections to the broader outside world. The SNOMED International Authority protects the purpose of SNOMED for clinical care and prevents drift of its purpose through its constitution, decision-making criteria, and the expertise of voting members. The SNOMED International Editorial Board is responsible for the scientific direction, editorial processes, and scientific validity of the terminology. The Editorial Board, composed of voting members and organizational liaisons, recommends guidelines for external input and field-testing. It also oversees the quality assurance process. The Editorial Board consists of both clinical content experts and medical informatics experts, with equal representation from the UK's National Health Service. In addition, liaisons from numerous associations reflect the vision of an integrated clinical vocabulary useful for dentistry, nursing, veterinary medicine, radiology, ophthalmology, public health, and other clinical specialties, and that is compatible with standards such as HL7 and DICOM. Participation of liaisons ensures scientific input from a range of clinical specialties and government agencies. Chaired by the SNOMED Scientific Director, this group provides scientific direction for and supports the work of a multidisciplinary team of modelers and data administrators.

CAP has identified an evaluation of the ICF as a priority for its 2004 worklist. The CAP is awaiting the results of our CHI Disability analysis. Once our analysis is complete CAP is interested in discussing priorities for adding significant missing content via the CAP established process.

<u>Acquisition</u>

How are the data sets/codes acquired and use licensed?

In June 2003 the NLM in the Department of Health and Human Services entered into a 5 year renewable licensing agreement with CAP to make SNOMED-CT available, free of charge, to any health care entity in the U.S. who agrees to the license terms. It is

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anticipated that by January 2004 SNOMED-CT will be included in and disseminated via the UMLS. The license permits the use of SNOMED-CT for all patient record uses and messaging.

Cost

What is the direct cost to obtain permission to use the data sets/codes? (licensure, acquisition, other external data sets required, training and education, updates and maintenance, etc.)

There is no acquisition cost due to the CAP & NLM agreement. We have no knowledge of the cost of implementing SNOMED as a source terminology from UMLS but it is our understanding that, once available, it can be extracted easily and then implemented as the current stand-alone version is. Successful implementation of the current version of SNOMED requires knowledge of the file and data structure that can be obtained from extensive provided documentation or training courses, offered for a fee, on-site or at the CAP offices on a regular basis. Similarly, full use of the hierarchies and relationships in SNOMED also require extensive training, education and in many cases extensive software changes. The United Kingdom has been working with CAP for 3+ years on implementation, Kaiser Permenate in US has for 5+ years, and various other prototype sites exist. To our knowledge, none have successfully used all features of SNOMED CT. Hence, no estimates on cost in this area can be offered. CAP has identified as an FY '04 priority mapping SNOMED-CT to the ICF.

Systems Requirements

Is the standard associated with or limited to a specific hardware or software technology or other protocol?

SNOMED CT is both vendor and platform neutral, and can thus be implemented into systems based on any technology.

Guidance

What public domain and implementation and user guides, implementation tools or other assistance is available and are they approved by the SDO?

An extensive set of education material is provided as well as training courses for SNOMED CT. Training and educational material are more limited for UMLS. Information and current draft documents can be found at www.snomed.org. Presently, there is no map between the SNOMED and the ICF.

Is a conformance standard specified? Are conformance tools available?

No. Discussion is under way regarding conformance-testing tools for use in the UK and subsequent use in the US, but they are at least one to two years away.

International Classification of Functioning, Disability and Health (ICF)

ICF belongs to the "family" of international classifications developed by the World Health Organization (WHO) for application to various aspects of health. The WHO family of international classifications provides a framework to code a wide range of information about health and uses a standardized common language permitting communication about health and health care across the world in various disciplines and sciences.

In WHO's international classifications, health conditions (diseases, disorders, injuries, etc.) are classified primarily in ICD-10 (International Classification of Diseases, Tenth Revision), which, for the most part, provides an etiological framework. Functioning and disability associated with health conditions are classified in ICF. ICD-10 and ICF are therefore complementary, and users are encouraged to use them together. The ICD-10 and ICF overlap and diverge. Both classifications begin with the body systems. Impairments refer to body structures and functions, which are usually parts of the "disease process" and are therefore also used in the ICD-10. Nevertheless, ICD-10 uses impairments (as signs and symptoms) as parts of a constellation that forms a "disease", or sometimes as reasons for contact with health services, whereas the ICF system uses impairments as problems of body functions and structures associated with health conditions.

The overall aim of the ICF classification is to provide a unified and standard language and framework for the description of health and health-related states. The ICF represents a revision of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), which was first published by the WHO for trial purposes in 1980. Developed after systematic field trials and international consultation between 1993-2000, it was endorsed by the Fifty-fourth World Health Assembly for international use on 22 May 2001.

The ICF includes 1,495 coded data elements. The ICF defines components of health and some health-related components of well-being (such as education and labor). The domains contained in ICF can, therefore, be seen as *health domains* and *health-related domains*. These domains are described from the perspective of the body, the individual and society in two basic lists: (1) Body Functions and Structures; and (2) Activities and Participation. As a classification, ICF systematically groups different domains for a person in a given health condition (e.g. what a person with a disease or disorder does do or can do). *Functioning* is an umbrella term encompassing all body functions, activities and participation; similarly, *disability* serves as an umbrella term for impairments, activity limitations or participation restrictions. ICF also lists environmental factors that interact with all these constructs as facilitators or barriers. In this way, it enables the user to record useful profiles of individuals' functioning, disability and health in various

domains. A draft version for Children and Youth has been developed and currently is being tested.

Acquisition
The ICF browser is available on the WHO website. The classification also can be purchased from the WHO Publications Center in book format ($45) or on CD-ROM ($135). For the time being WHO issues license agreements for commercial and institutional use of ICF on a case by case basis. WHO is in process of developing a comprehensive licensing policy for ICF, including the terms for inclusion in the UMLS.

How are the data sets/codes acquired and use licensed?
(See above)

Cost

What is the direct cost to obtain permission to use the data sets/codes? (licensure, acquisition, other external data sets required, training and education, updates and maintenance, etc.)
Although some educational material is available on the WHO web site, training is generally carried out by the WHO Collaborating Centres for the Family of International Classifications (FIC; the North American Center is housed at the National Center for Health Statistics, CDC). A training tool, Code ICF, has been developed by the North American Center with the expectation that it will be posted on the WHO web site in 2004. A Procedural Manual and Guide for Health Professionals for a Standardized Application of the ICF currently is under development and testing. The ICF has been available for only two years, and applications are still being tested and developed. To date, no updates have been made to the classification, but updating will be the responsibility of the network of WHO FIC Collaborating Centres in conjunction with WHO.

Systems Requirements

Is the standard associated with or limited to a specific hardware or software technology or other protocol?

No

Guidance

What public domain and implementation and user guides, implementation tools or other assistance is available and are they approved by the SDO?
See above. All official training tools and user guides will be approved by WHO, which serves as the Standard Development Organization for the WHO FIC.

Is a conformance standard specified? Are conformance tools available?
No.